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# Socio-economic challenges faced by widows living with HIV/AIDS in New Delhi, India

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***Abstract:*** *With an estimated number of 40 million, India is the home to the largest number of widows in the world. Widows are often subjected to deep societal, cultural, psychological and economic deprivation in the name of traditions. Deep seated patriarchal roots and unquestioned customs place widows at a defenseless position. They are often disdained, stigmatized, abused and marginalized from the mainstream. A diagnosis of HIV further exacerbates the challenges of widowhood as now these HIV positive widows battle dual marginalization: being a widow and suffering from HIV. Diagnosis of HIV coupled with cultural factors which look down upon widows adds on to already existing inferior status of widows. Paucity of literature related to HIV positive widows led to the conception of the present study. The present paper attempts to study the impact of HIV positive status upon the social and economic lives of HIV positive widows. Sample of 50 HIV positive widows was selected using Purposive Sampling from HIV clinic at New Delhi, India. Semi-structured interview was used to collect the data. Data was analyzed both quantitatively and qualitatively. The results drew attention towards the age-old thought process of blaming the woman for the death of her husband as widely prevalent. The widows were subjected to intense forms of physical violence, rejection and abandonment. HIV was seen with "sexual connotations" which resulted in stigma and discrimination. However, economic instability emerged as a towering challenge among the respondents amidst already prevailing conditions of abject poverty. An interesting finding concerning the loss of self-identity among the respondents emerged. It was found that the respondents had no understanding of their own identity and meaning of life. This finding is of much significance as it indicates deeply engrained patriarchal roots in society where the self of a woman is not allowed to evolve and thus, get remained to the children, husbands and others around her.*

Keywords: HIV, Widows, Socio-economic challenges, Stigma and discrimination, Economic instability, Self-identity

Overtime, HIV infection has been growing among women at an alarming speed. Unfortunately, in India, HIV epidemic continues to shift towards women with 25% of all the HIV positive persons now estimated to be women and an accompanying increase in vertical transmission (Bhosale, 2004). Also, given the trend in the HIV epidemic in India and elsewhere, it is possible that the number of HIV positive cases of women would escalate further before they stabilize or decline (Sahu, 2015). The escalating number of women who are acquiring this disease tells the story that their lives will be forfeit, put at further risk and shall be doomed if it continues to remain unchecked.

The gender implications of HIV/AIDS is becoming increasingly important with rising HIV incidences among women – in view of that fact that heterosexual activity constitutes the main mode of transmission of HIV. The AIDS epidemic has had a unique impact on women, which has been exacerbated by their biological vulnerability to HIV infection. Gender disparities in terms of access to education, resources, income, political power, coupled with the incidence of sexual violence, coercion, social dislocation in conflict situations or owing to migration, serve to increase the risk of HIV through unprotected sex (Kalpana and Iyer, 2013).

## Widowhood and HIV

With an estimation of 40 million widows (Sahoo, 2014), India is home to the largest number of widows in the world. In India, widows are subjected to patriarchal customary and religious laws which put them as a prey for abuse and exploitation to no end and from all ends.

Widows face specific difficulties in seeking economic opportunities due to lack of access to invisible productive assets, weak bargaining power, illiteracy and limited access to institutional credit. Particularly widows with young children have the burden of domestic work too. The restrictions on residence, ownership, remarriage, and employment put widows in a situation of acute dependence on economic support from others (Ramanamma & Chaudhari, 2004). A study by Kowalski and Bondmass (2008) described psychological and physiological symptoms of grief in widows. Physical symptoms included pain, gastro-intestinal problems, sleep disturbances, and neurological issues. Psychological symptoms were reported as depression, anxiety, and loneliness.

Life of a widow is headed for a doom once she acquires HIV. As if widowhood was not enough for her to bear the brunt of life, HIV positive diagnosis further compounds the problems they face as now they get doubly marginalized: by virtue of being a widow and of being HIV positive. Since HIV is laden with moral and ethical connotations, it makes HIV infected widows vulnerable to societal reactions (Monga & Dassi, 2015).

In many societies being socially ostracized, marginalized, and even killed are real potential consequences of exposing one's HIV status. Most widows living with HIV live in poverty and struggle with complex economic issues. Most of their energy is spent meeting basic needs of life which take priority over health issues. Many widows experience a variety of emotions related to infecting their children and /or the mode of transmission for themselves (Sachdeva & Wanchu, 2006).

The idea of the present study emerged from the understanding of the patriarchal structure of our society which is propelled not only by the males but also is equally fuelled by the elderly females who themselves suffered and now reached the stage of cementing patriarchal roots in the name of tradition and culture.

The present study took into consideration the most neglected section of our population – the widows suffering from a deadly disease HIV. The purpose of targeting this population was to explore the socio-economic challenges faced by this ignored population which is suffering not only at the hands of their own families but also have received step-motherly response from the government authorities.

## Methodology

Using purposive sampling, 50 widows living with HIV were selected from Antiretroviral Clinic (ART Clinic) located at a government hospital in New Delhi, India. HIV infected widows who were already registered with the ART Clinic for more than one year and had acquired HIV from their spouses (as per the hospital records) were only included in the sample while the women with any psychiatric or any other grave medical illness were excluded. Since the data collection and data transcription was undertaken simultaneously, it was realized that no new information emerged after interviewing more than 40 respondents. Hence, the sample size was rounded off to 50 respondents. At the point of saturation, no new information emerges and the rich and dense theoretical data is already achieved (Glaser & Strauss, 1967; Strauss, 1987).

A pre-tested semi-structured interview schedule was used to collect the data. The tool was translated into Hindi language since all the respondents were from the northern region of India where Hindi is the spoken language.

Data collection commenced with approval from the ethics committee of the government hospital. Semi-structured interview schedule was administered after taking a written informed consent from the respondents. During interviews, which lasted from one hour to one hour thirty minutes, the researcher acted as a facilitator rather than throwing a volley of questions. All the interviews were tape-recorded using a Dictaphone.

Analysis:

The acquired data was analyzed both quantitatively and qualitatively. As a part of quantitative analysis, percentages and frequencies were calculated to generate socio-demographic profiling of the respondents. For qualitative analysis of the narratives, the following steps were followed which were described by Attride-Stirling (2001); (i) Coding the material, (ii) Identifying themes and (iii) Constructing networks.

Criteria of credibility as defined by Lincoln and Guba (1985) were adhered to in the study. The researcher assured that the line of questioning pursued in the data gathering sessions and the methods of data analysis were derived, wherever possible, from those that have been successfully utilized in previous comparable researches. Also, frequent debriefing sessions were undertaken by the researcher with experts in the area which has been suggested as an important tool to enhance the credibility of the research (Shenton, 2004).

**Profile of the respondents**

| | |
|---|---|
| Mean Age | 38.6 years (26 years - 47 years) |
| Educational Status | Illiterate – 44%<br>Primary – 26%<br>Middle – 22%<br>10+2 – 6%<br>Graduate – 2% |
| HIV since (mean number of years) | 2.3 years (14 months-5 years) |
| Duration since husband's death (mean number of years) | 4.2 years (13 months-6 years) |
| Occupational status | Homemaker – 56%<br>Daily wage worker – 10%<br>Private salaried job/maid – 26%<br>Petty business – 8% |

| | |
|---|---|
| Other sources of income | Widow pension – 42%<br>HIV pension – 96%<br>Children are earning – 36%<br>Support from family – 64%<br>Many respondents had income from overlapping sources. |
| Average monthly income from all sources (in rupees) | Rupees. 1000 – Rupees. 5000 |

**Widowhood and associated challenges**

The respondents, regardless of their age, reported of bearing the brunt of losing one's husband. The age old thought process of blaming the daughter-in-law for death of family's son was prevalent among the families. Nearly 12% of the respondents were abandoned by their in-laws' and were left alone with no social security. These abandoned women found shelter at their natal family, however, social marginalization along with several cultural restrictions followed even at natal families. The women who were still residing with in-laws post their husbands' death reported of facing intense deprivation and stigmatization in the name of ritual and religious symbolism. One of the respondent reported, "*My in-laws have thrown me out of their home as they hate me. They say that I perform black magic and if I continue to stay with them, I will kill their other sons as well."* There are several studies which report that widows undergo deprivation in social, emotional and cultural terms (Ramanamma & Chaudhuri, 2004).

Blame of death of their son was common among the respondents. One of the respondent informed, *"Everyone blames me and my natal family for my husband's death. My mother-in-law has tagged me as kulta and often call me dian. At times, they hit me badly."*

Respondents recollected that restrictions were imposed upon their everyday life and on their clothing habits. They also informed that participation in social functions or any kind of celebrations or festivals was reduced as now they were considered as a bad omen. As reported by one of the respondents, *"After my husband's death, I have stopped wearing any jewellery. I am not allowed to talk to any male member. Throughout the day, I just keep myself to my room with no interaction with anyone. I was not even allowed to attend my brother's marriage."*

However, analysis revealed interesting findings. While just 5% of the respondents felt utterly disturbed with such social marginalization caused due to their widowhood, rest of the respondents practiced "self imposed aloofness." These respondents, to some extent, considered it correct to be under restriction and limitations as they being women should observe restraint and control over their wishes and desires. For instance, one of the respondent said, *"After my husband's death, its not good on my part to dress up and go around. As a woman, I should keep a check on my desires now. It's the rule of our society and we should follow it."* This statement brings forth the deeply embedded patriarchal structure in our society which our women have now made a way of life.

**Abandonment and rejection**

Results revealed that among all the respondents, 68% shared constrained relationship while 12% had absolutely no contact with the in-laws. They were subjected to total abandonment by their in-laws and no contact existed.

Financial liability that the respondents posed upon the in-laws was cited as as the major reason for hostile relationship between the respondents and the in-laws. Almost 69% of the respondents shared the view that their in-laws did not want to share their financial resources with the respondents. One of the women stated, "*My in-laws are cruel. They say that I and my children are a financial burden upon them and they don't wish to spend money on us. They have thrown us out of their house. I am not in contact with them anymore."* Another woman also shared a similar concern, *"My in-laws don't understand about my illness. My mother-in-law is a miser woman who has taken away all my jewellery that I had got in wedding. They have also taken away my share of property. I forcefully sit at their place and get beaten everyday but still I don't move away otherwise they will eat away my share."* Monga and Dassi (2015) also shared similar results in their study where they found that the reason for rejection was dependence of widow and her children upon in-laws which adds up to the already existing economic instability of the family.

Stigma and discrimination because of the diseases and associated "sexual element" was also another reason for rejection. Respondents shared that the fear of spread of disease by touching, sharing clothes and talking persisted among the family members which led to further discrimination.

Physical assault in the form of slapping, hitting with bat, pulling hair, head banging on the wall etc was shared by 80% of the respondents. In all these cases, the mothers-in-laws were the major instigators.. One of the respondents informed, *"I used to be beaten black and blue by my mother-in-law and brother-in-law. They used to kick me and hit my head on the wall."* Further, nearly 35% of the women reported restriction of movement and were not allowed to go anywhere and speak to anyone in the locality. Also, 5% of the women

reported that there were attempts to kill them by feeding them poison or burning them.

**Economic predicament**

Analysis revealed financial crunch as the most towering challenge battled by the respondent. This concern was unanimous to all the respondents, whether working or stationed at home. The average monthly income from all sources was between Rupees. 1000 to Rupees. 5000. As informed by one of the respondents, *"I am facing deep financial crunch. I have no income from anywhere except from my small shop. How do I manage my home and three children without money."* Sharing the same pain, another respondent stated, *"My youngest son is also HIV positive. He requires good and nutritious food and milk. I don't have anything with me to make even one time meal for him. Milk is very expensive."*

In fact, during the course of the interviews, it was established that more than being concerned about their HIV positive status, the major cause of concern was financial distress. As informed about one of the respondents, *"My financial problems are much bigger than this disease. I need money at every moment for food, child's education etc. Medicines for my disease are free at the hospital. I am extremely worried about meeting my financial needs.*" Similar view was shared by another respondent, "*I pray to God everyday to support my children financially. I don't even think of my disease. Just remain concerned about the money as I cannot even manage food for one time for my children."*These verbatim highlight the deep concern and worries pertaining to the financial crisis over their disease which they even tend to forget against the herculean economic instability.

It was found that 56% of the respondents were homemaker and thus had no income which they were earning. Their main source of income came from their children who were working and at times, received support from their natal families. 26% of the respondents were working as house maids/cook in the nearby rich localities and thus could earn minimal amount of money. While 10% of the women were daily wage workers, another 8% of them had a petty business (small shop, tailoring). A staggering 96% of the respondents received their HIV pension of Rs. 1000 per month. This pension scheme was initiated by the NACO towards the interest of HIV positive population. Also, 42% of the respondents received their widow pension which ranged from Rs. 300 per month to Rs. 1000 per month depending upon which state they belonged to. Women from Delhi had the highest widow pension.

It was further found that about 64% of the respondents received financial support, every now and then, from their natal families as well as neighbors. However, unfortunately, in-laws did not show any support in terms of financial help towards these respondents. One of the respondent stated, *"My in-laws have thrown me out of the house and the say that they cannot take care of my financial expenses. They have grabbed my rights in family property."* Similar findings were reported in other studies which highlighted support of natal families and neighbors in financial distress while abandonment by the in-laws (Monga & Dassi, 2015; Mrudula & Vindhya, 2009; Dawar & Anand, 2009).

**Loss of self-identity in worries for the children**

During the course of interviews with the respondents, the researcher realized about "no self-identity" which existed among them. It appeared that these respondents were far away from the very basic understanding of what self-identity is. It was striking to learn that all the respondents could not relate to the idea of "thinking about their own self." It appeared as if this concept was alien to them. Despite several efforts to explain them the essence of the question several times, it emerged that the very idea of self-identity was beyond their understanding.

Interestingly, the idea of self-identity was confounded and intertwined with their children's happiness. These respondents didn't ever think about their own desires and wishes and realized contentment in the happiness and care of their children. For instance, one of the woman stated, *"I don't understand what you are trying to ask me. I just feel worried about my children and want them to get settled in life. That will give me eternal bliss."* Another woman informed, *"I don't think about myself. The whole and sole meaning of my life is to do something for my children. If they remain happy, I achieve everything in my life."*

This lack of understanding of "self" may be indicative and suggestive of deeply engrained patriarchal roots in our society where the self of a woman is not allowed to evolve and thus, get remained to the children, husbands and other around her. Her own wishes, desires and understanding are stifled to no end and, in most of the cases, are suffocated to death. It was interesting to how the respondent's meaning of life is entangled with the happiness of her children. The respondents felt contented and satisfied if the children were happy. Their own happiness stood no meaning for them.

It was also reported by many women that death of their husbands left them psychologically and emotionally vulnerable, apart from financial crisis, which led them to question meaning of their life. When the spouse was alive, husband and wife functioned as a couple and could easily integrate into the societal framework. However, after the death of their husbands, the widows find them in the state of insignificance (Pickard, 1994).

The discussion led to the emergence of a number of worries that were shared by these respondents

towards their children. All the women voiced out similar concerns. The major causes of worry that came out were: education for their children; good and adequate nutritious food for children; safety and security of children, particularly girl child; marriage of children; meeting petty desires like clothes, shoes, toys etc; health of the children; and seeking share in family property in the name of children to secure their future. As informed by one of the respondent, *"I go to work everyday and my daughter stays alone at home. I always feel worried about her safety. But I don't understand how to help my situation."* Another respondent stated, "*My daughter is marriageable now. But I get worried how to find a groom for her. I don't have enough financial resources to sustain everyday life, what to talk of marriage now."* Worries about the children has been highlighted in many studies (Luginaah et al., 2004; Mrudula & Vindhya, 2009). These studies highlighted that maintaining a happy environment for their children in spite of the devastating effects of HIV remained most important concerns for HIV positive widows.

**Discussion**

The present study brought to light that apart from being subjected to harsh conditions because of their widowhood, WLHIV are further challenged with HIV which compounds their problems manifold. It was revealed that majority of the respondents were subjected to abandonment and rejection by their in-laws. Previous studies (Monga & Dassi, 2015; Korner, 2007; Obi & Ifebunandu, 2006; Gujjarappa et al., 2004; Shah & Shah, 2000) too have reported negative responses by the in-laws. The finding that financial liability which these widows posed upon their in-laws was one of the major causes of abandonment among other causes of stigma associated with the illness shows corroboration with studies by Luginaah et al., (2005), Subramanian et al., (2012) and Dewan et al., (2012). Financial crisis emerged as one of the humongous challenges in the lives of widows living with HIV/AIDS. For WLHIV, the situation becomes grim as in the absence of husband, income generation opportunities turn bleak. Female-headed households, apart from lacking safety and security, also develop pitiable financial crisis. Past researches (Momsen, 2002; Chant, 2007; Posel, 2001 in Schatz et al., 2011) have suggested that female-headed households are "poorest of the poor" and are often reported of being more dependent and having poor socio-economic status in society. Further, it was revealed that the roots of patriarchy were so deep seated that the respondents had no understanding of their own self-identity. Their self-identity was entwined with the happiness of their children which took the first seat. Simone de Beauvoir brings to light that a man defines the woman in relation to himself and she does not have an independent identity. According to Beauvoir (Beauvoir, 1949), a woman is not regarded as an autonomous being but always in relation to a Man. Thus, the woman becomes the Other where her own identity gets compromised and dissolved in other identities of being a wife, a mother, and a daughter-in-law.

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